CHS Office of Research and Education (ORE)

NHMRC Draft Statement on Consumer and Community Involvement in Health and Medical Research (2025)

Hospital-based research perspective

Overall position

Canberra Health Services (CHS) welcomes the intent of the NHMRC Draft Statement to set high expectations for involving consumers and community in health and medical research.

Hospitals already operate under enforceable consumer and community involvement governance requirements for clinical trials through the National Clinical Trials Governance Framework (NCTGF). As this framework is expected to expand to encompass all hospital-based research, alignment between the NHMRC Statement and the NCTGF is important. This will avoid duplication, reduce complexity, and ensure consistency in accreditation, funding, and reporting.

Strengths of the Draft Statement

- Clear values and principles: Respect, equity, inclusion, transparency, and safety provide a solid foundation.
- Strong positioning of involving consumers and community: The Statement promotes inclusion across all stages of research, from design to translation.
- Sector-wide applicability: Covers all health and medical research, reinforcing a culture shift towards routine involvement.
- Signal of future funding requirements: Encourages proactive cultural and systems change in advance of mandates.

Areas for alignment

- **Terminology**: The Draft Statement uses “involvement,” whereas hospitals are already required to align with the NCTGF language of “partnering with consumers.” Consistent or similar terminology may reduce confusion and strengthen uptake. Additionally, CHS has elected to refer to “consumers,” “carers” and “community” in the context of the NCTGF.
- **Integration with accreditation**: The NCTGF embeds partnering with consumers as an accreditation requirement for clinical trials. The NCTGF is expected to expand to include all hospital-based research in the next 5 years. The NHMRC Statement may wish to reference alignment with accreditation frameworks to streamline implementation.

Areas for improvement

- **Clarity on scope of accountability**: Hospitals already apply governance across corporate, clinical, and research structures. The Draft Statement should more clearly recognise hospital boards and executives as accountable for partnering across all research.

- **Resourcing and remuneration**: Effective partnering requires investment. The Draft Statement should emphasise the need for budgeted resources for consumer remuneration, training, and support.

- **Monitoring and reporting**: The Draft Statement should recommend consistent indicators for consumer involvement (e.g. percentage of studies with consumer involvement, changes made due to consumer involvement, consumer research partner satisfaction).

Suggested guidance resources and national policies/guidelines

To support implementation, CHS recommends that NHMRC consider developing or endorsing national guidance and resources to complement the Draft Statement, including:

- National consumer remuneration guidelines for health and medical research, harmonised with hospital and university policies.

- Standardised consumer involvement and partnering indicators and reporting templates, enabling consistent monitoring across research institutions.

- Training modules and competency frameworks for researchers and consumers to build skills in effective partnering.

- Practical tools and exemplars, such as model consumer involvement/partnering plans, case studies, and evaluation frameworks.

- Cross-sector alignment policies or position statements linking NHMRC expectations with the NCTGF, NSQHS Standards, and major funding agency requirements.

Conclusion

The Draft Statement provides an important opportunity to set national expectations for involving and partnering with consumers, carers and community in research. For health services, alignment with, or reference to, the National Clinical Trials Governance Framework (NCTGF) is important, given its current role in clinical trials accreditation and its expected expansion to all hospital-based research.

By refining terminology, clarifying accountability, and embedding requirements for resourcing, monitoring, and reporting, the Statement can drive meaningful cultural, and systems change. With complementary national guidance and tools, NHMRC can enable hospitals and clinician researchers to implement consumer and community involvement and partnership approaches in a consistent, practical, and sustainable way.

Appendix A: Answers to survey questions

Expectations of Involvement

Does the Statement set clear and suitable expectations that consumers and community will be involved in all stages of research?

Yes. The Draft Statement makes strong commitments to routine involvement of consumers and community across the research cycle, from design to translation. For CHS, this is consistent with hospital-based research governance under the National Clinical Trials Governance Framework (NCTGF). Alignment between the Statement and accreditation frameworks will further strengthen uptake and implementation.

Likewise, the Statement aligns with the CHS Partnering with Consumers and Carers Policy and CHS Office of Research and Education (ORE) Partnering with Consumers and Carers in Research initiatives.

Values and Principles

Does the Statement clearly explain the key values and principles that ensure effective consumer and community involvement?

Yes. The values of respect, equity, inclusion, transparency, and safety are appropriate and provide a solid foundation. The principles of partnership, mutual benefit, and equitable inclusion are well-articulated.

Comments:

- The Statement should highlight the importance of resourcing, training, and remuneration for consumers and carers.
- Consistency in terminology - particularly the use of, or reference to, “partnering with consumers and carers” - may reduce confusion and align with accreditation requirements.

Roles and Responsibilities

Does the Statement clearly explain the shared roles and responsibilities of all involved?

Partly. Shared roles are described, but more emphasis is needed on accountability at hospital and academic executive and board levels.

Does the Statement clearly explain the roles and responsibilities of consumers, carers, communities, and consumer organisations?

Yes. Their role in shaping priorities, influencing design, and disseminating outcomes is clear. Stronger emphasis on resources and training would improve effectiveness.

Does the Statement clearly explain the roles and responsibilities of researchers?

Yes. Researchers' responsibilities are well defined but should explicitly include planning for involvement at the outset of projects, with time and budget allocated.

Does the Statement clearly explain the roles and responsibilities of research institutions?

Partly. While roles are outlined, the Statement should go further in recognising institutional accountability for safe, inclusive, and well-resourced involvement.

Does the Statement clearly explain the roles and responsibilities of research funders?

Yes. The responsibilities of funders are clear, but expectations could be strengthened by embedding requirements for resourcing consumer remuneration, supporting training, and providing national guidance.

Implementing the Statement

What else is needed to support the effective implementation of consumer and community involvement?

- National consumer remuneration guidelines, harmonised across hospitals and universities.
- Standardised involvement indicators and reporting templates.
- Training modules and competency frameworks for researchers and consumers, carers and community.
- Practical resources such as model consumer and carer involvement/partnering plans, case studies, and evaluation frameworks.